



Emory University School of Medicine Alzheimer's Disease Research Center

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Celebrating Our Partnerships - *By: Ezinna Anosike*



The Emory ADRC has been dedicated to partnering with Emory researchers, global research institutions and local and national advocacy groups to make progress in the study of Alzheimer's disease. Unveiling the mystery behind the cause of the disease to target prevention and discover more effective treatment models that enhance the quality of life of affected individuals and families has been the ADRC's goal. The most formidable and enduring partnership has been that of the research participants. Since the inception of the center at Emory over a decade ago, a cohort of enthusiastic volunteers have

given time and shared information that is used by our researchers to understand how Alzheimer's disease and related neurologic conditions affect individuals and progress over time.

"The consistent commitment is celebrated by our research staff each time the ADRC is able to contribute scientific data on Alzheimer's and related research."

Advancements in research are possible because of the ongoing commitment of volunteers who take part in research initiatives knowing that findings may be years to come in the future. The gift research volunteers give is one of compassion to aid family members and future generations.

At the ADRC, we are aware of the gift from our research volun-

teers. We have participants who have been regularly involved in the **Emory ADRC Honor Registry** for over a decade. The Honor Registry is a longitudinal observational study which calls for long term involvement. The aim of the study is to understand age-related changes in neurologic function affecting memory. Volunteers and their study partners come annually to participate in studies; some come multiple times a year. Participants in the Research Registry become part of a cohort often contacted for involvement in other ground breaking research studies. The consistent commitment is celebrated by our research staff each time the ADRC is able to contribute scientific data on Alzheimer's and related research.

Tomorrow's Leaders in Alzheimer's Disease Research Award

JAMES LAH, MD, PHD



On July 30, 2008 at the International Alzheimer's Disease Congress in Chicago, James Lah MD, PhD was recognized as one of the inaugural recipients of the "Tomorrow's Leaders in Alzheimer's Disease Research" award. Dr. Lah was one of three promising investigator's who received the award for having made pivotal contributions to early detection, treatment and prevention of Alzheimer's disease. The sponsoring organizations, the Cure Alzheimer's Fund, the Alzheimer's Association and the Lou Ruvo Brain Institute modeled the \$100,000 awards on other genius grants, and the funds may be used for any purpose at the discretion of the awardees.

In addition to directing a lab at the Emory

Center for Neurodegenerative Disease Dr. Lah also serves as the Clinical Core director of the Emory Alzheimer's Disease Research Center. This involvement in both basic science and clinical research allows Dr. Lah the unique opportunity to further the mission of the Emory Alzheimer's Disease Research Center to seek cures through basic laboratory research, to bring new diagnostic methods and treatments into the clinic to provide patients and families with comprehensive and state of the art care that includes access to cutting edge advances.

The Emory Alzheimer's Disease Research Center and the Emory Center for Neurodegenerative Disease bring together researchers with expertise from a variety of disciplines and departments, including Neurology, Genetics, Pharmacology, Cell Biology and Pathology working together to share resources and ideas. The Emory "team" approach fosters scientific discoveries aimed at enabling earlier and more accurate diagnosis and development of more effective treatments. Dr. Lah's research is driven by the goal of understanding the basic pathogenic mechanisms in neurodegenerative disorders. Spe-

cific topics of interest include regulation of cellular processes and the characterization of new genes involved in Alzheimer's disease, Parkinson's disease, Frontotemporal Dementia, and other neurodegenerative disorders. These questions are being addressed in a variety of models and using a variety of state of the art research technologies. Genetic studies, using patient samples collected through clinical activities at Emory, are being pursued through a novel partnership with a leading genomics company based in Iceland (deCODE Genetics). Combining understanding of basic mechanisms with knowledge of clinical manifestations and neuropathology offers the greatest hope for advancing research to improve treatments for complex neurodegenerative diseases.

This award is a well deserved recognition of Dr. Lah's compassion and commitment to research. He intends to use the award money to support the Registry for Remembrance, a new Atlanta-based, community-academic partnership that seeks to improve the understanding of genetic risk factors for Alzheimer's disease among African Americans.

Dealing in Emotional Truth

KEN HEPBURN, PH.D.



Caregivers frequently report that their loved one says – and clearly believes – things that are untrue. The person may, for example, say that she plans or wants to visit her parent that afternoon (but the parent

died many years ago). The person may say he's looking forward to visiting a country home that was sold long ago. This kind of incorrect thinking can take other forms that are sometimes less clearly associated with losses in thinking ability (for example, asking questions or telling stories over and over, making things up, or even using the same phrases over and over).

Statements like these emerge from the confusion and cognitive losses the person is experiencing. They may be triggered by something the person sees or hears, or they may just come from a random recollection. In any case, in these situations, the caregiver is faced with having to respond.

In these moments, caregivers may feel confronted with an impossible choice. They can either confront the person about the factual truth of the statement, or they can deal in what they may feel would be a deception – pretend that the statement is true and make something up to placate the person in the moment. To many, this latter choice feels like lying to the person, and that makes caregivers understandably uncomfortable.

There are a number of reasons why confron-

tation and insisting on the truth of a statement would be unproductive. Given the losses the person is suffering, it is likely the effort to “convince” the person (i.e., reason with him/her) will be unsuccessful. Almost certainly, the person will not remember whatever is at issue. Moreover, asking the person to look at an uncomfortable truth might lead to greater confusion and upset.

From the perspective of the savvy caregiver, it is preferable to validate and deal with the “emotional truth” of the situation. Validation is a strategy pioneered by Naomi Feil that accepts that what a person says may be a clue to what s/he is feeling, regardless of the accuracy of the statement. Validation directs caregivers to use the person's words – and the emotion underlying them – as a way to connect with the person. Validation here means that there is a recognition of the genuineness of feelings and of their source. In a way, validation is a special kind of listening – it is a listening to the feelings and yearnings of the person who may no longer be able to reliably express them. The Validation Training Institute website (<http://www.vfvalidation.org>) provides further information about validation therapy. The site also provides links to books and articles on the topic.

The content you have to work with in validation is often content that is contrary to fact. Persons may speak of family members who are dead or distant (a daughter's visit; yearning for a parent). They may speak of events long past or that never happened (a wedding or family event or trips to exotic places). They may speak of events or occurrences that will never happen (getting a driver's

license; going to a summer place).

In validation, you accept the person's feeling about the content and then use that feeling to move the person to a different activity, one that may involve the content in some other way. For example, a person for whom you are caring might say to you “Mary (her daughter) is coming to visit me this afternoon.” You know, however, that You could respond with the “truth” of the situation (the daughter lives out of town and hasn't visited in six months) or you could look for a way to respond to the fact that, for whatever reason, the person's family has come to mind. So, taking a validation approach, you might respond: “I miss Mary, too. Let's look at some pictures of her and your grandchildren.”

What you are hoping to accomplish is that the person will take pleasure in the pictures and the feelings of family they might stimulate and that she will be diverted from thinking that her daughter is coming to visit.

The suggestion is not to lie (don't, for instance, say that the daughter will be visiting tomorrow or next week – in the hope she will forget the whole thing). Instead, search for what the person may be feeling regarding the topic he or she is bringing up, and do something that works positively with that feeling. So, whether the person is talking about a long lost parent or place or a distant child or friend or a favorite spot or pastime, engage the person in something that taps into those feelings. Try to get the person to talk about the topic; look at pictures that relate to the topic; tell your own stories about the topic. Let the person have time in the emotional moment, and then work to move him/her on to some other task or activity.

The Personal Benefits of Research Participation

By: Susan Peterson-Hazan, MSW



Kristi Ledford and her mother, Sue James, learned about a clinical trial when Ms. James was diagnosed with early Alzheimer's disease at Emory. “When Mom learned about the study her response was amazing” said Kristi. “Mom said if she

could help someone else avoid this disease she had an obligation to participate.” Research volunteers often voice their desire to help their children, grandchildren and other people at risk for Alzheimer's as one reason they decide to participate in a clinical trial.

“For us, there were unexpected benefits,”

said Kristi. “We live in Canton, Ga., so it took a significant block of time to travel to Emory. But this became a special trip with Mom because we always went to Mary Mac's for lunch after the appointment. It was a day we looked forward to every three months.

“Another unexpected benefit was the extra time we were able to spend with the experts at Emory,” said Kristi. “Because we saw the researchers fairly often, we had the opportunity to ask questions and get insights that we would not have gotten otherwise. Having the research team's expertise to help us deal with the disease was invaluable to our family.”

Most clinical trials are double blind studies. That means that some participants get the trial substance and some do not. “Although we didn't know for sure which substance she received,” Kristi said, “we felt like the medi-

cations helped Mom.” Most trials want participants to be stable on the current Alzheimer's medications such as Aricept, Razadyne, Exelon or Namenda for at least three months. Usually hundreds of people are enrolled in a study across the country. Ms. James enrolled in a study that took 18 months to complete.

Ms. James died a year after she completed the study and before the results of the study were known. “The study results were surprising” said Kristi. “The treatment did not slow the progression of the disease.” Kristi paused for a few seconds then said, “I miss Mom everyday. I know we honored our mother's wishes by enrolling her in the study and by donating her brain to the Emory brain autopsy program. She wanted to help others avoid this terrible disease.”

Clinical Trials & Research Studies · Fall 2008

Research Study	Eligibility	Contact Person
Vaccine Trials	Diagnosis of mild to moderate Alzheimer's disease Age 50 and older Stable on medications for Alzheimer's for three months Study partner available to accompany to all visits	Deborah Stout 404-728-4936 dstout@emory.edu
ELND005 in Patients with Mild to Moderate Alzheimer's Disease	Stable on medications Study partner available to participate in all study visits 18 month study Willing to undergo lumbar puncture	Deborah Stout 404-728-4936 dstout@emory.edu
RAGE Inhibitor Study (RAGE = Receptor for Advanced Glycation Endproducts)	Diagnosis of mild to moderate Alzheimer's Disease Stable on Alzheimer's medication for 4 months Study partner available for all visits 21 month study	Ann Snider 404-728-6541 asnider@emory.edu
High Dose Aricept Sustained Release Study	Moderate to severe Alzheimer's disease Stable on 10 mg of Aricept for at least 3 months Age 45 – 90 Study Partner available for all visits	Ann Snider 404-728-6541 asnider@emory.edu
Neuroimaging study	Diagnosis of Alzheimer's disease Or no memory or thinking problems Age 50 years and older right handed	Andrea Kippels 404-728-6443 ajkippe@emory.edu
Emory ADRC Honor Research Registry Longitudinal study of changes in memory and thinking skills	Aging people over 65 with no memory problems People of any age with mild cognitive impairment, Alzheimer's disease or other forms of dementia Enthusiastic about participating in additional research studies at the Emory ADRC Study partner available to participate in visits	Katelyn Perkins 404-728-6590 kgperki@emory.edu
Lewy Body Disease	Diagnosis of probable or possible Lewy Body Dementia Stable on medications Willing to spend 72 hours in a sleep research lab Willing to undergo lumbar puncture	Donald Bliwise, Ph.D. 404-728-4751
Memory Rehabilitation Intervention in Amnesic Mild Cognitive Impairment	Diagnosed with amnesic mild cognitive impairment Study partner who can attend all cognitive rehabilitation sessions Lives within 45-driving minutes of Wesley Woods Health Center at Emory University and/or will commit to come to all training sessions	Noah Duncan 404-728-6544 nduncan@emory.edu
Cognitive Rehabilitation in Mild Cognitive Impairment	Diagnosed with mild cognitive impairment Total of 7 visits Willing to undergo MRI scan	Ben Hampstead, PhD 404-712-5667 bhampst@emory.edu
Vision & Alzheimer's Disease	Diagnosis of Alzheimer's Disease 1 or 2 study visits Participants will answer questions about lights or pictures that appear on a screen & wear a headset that covers the eyes and shows a realistic scene.	Audrey H. Gutherie, PhD 404-321-6111 ext 1323 ahgutherie@yahoo.com
Research Study: Registry for Remembrance <i>an initiative to increase awareness and participation in neurology research</i>	Ethnic persons with African Ancestry Aging people over 60 with no memory problems People of any age with mild cognitive impairment Alzheimer's disease or other forms of dementia Study partner available to participate in visits	Ezinna Anosike 404-728-6395, eanosik@emory.edu

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Researchers Find Conclusive Evidence of Alzheimer's-Like Brain Tangles In Primates



Researchers at the Yerkes National Primate Research Center, Emory University, have discovered the first conclusive evidence of Alzheimer's-like neurofibrillary brain tangles in an aged nonhuman primate. The unprecedented

finding, described in the online issue of the *Journal of Comparative Neurology*, has the potential to move the scientific community one step closer to understanding why age-related neurodegenerative diseases, such as Alzheimer's disease, are uniquely human and seem to never fully manifest in other species—including our closest evolutionary relative, the chimpanzee.

Lead researchers Rebecca Rosen, a doctoral student who is conducting her research at Yerkes, and Lary Walker, PhD, a neuroscientist and research professor at Yerkes, in collaboration with colleagues at UCLA, made the unanticipated finding during a routine post-mortem study of an aged, female chimpanzee that died of natural causes. The researchers also discovered deposits of beta-amyloid protein in plaques and blood vessels of the chimp's brain tissue, although these changes were infrequent compared to Alzheimer's disease in humans.

"We've seen these plaques in aged chimpanzees before, but this is the first time researchers have found both hallmark features of Alzheimer's disease—plaques and neurofibrillary tangles—in a nonhuman primate," explains Walker.

As many as five million Americans are living with Alzheimer's disease, the most

common form of dementia. A cure has eluded researchers, and the disease is considered progressive and fatal. Brain plaques and tangles associated with the disease are prime suspects in damaging and killing nerve cells that cause memory loss and dementia.

"Alzheimer's disease has a huge number of potential causes," says Rosen. "By studying the development of human features of the disease that occur naturally in nonhuman primates, we may be able to isolate what makes people so susceptible to neurodegenerative disease and identify targets for therapeutics."

The research reported in the *Journal of Comparative Neurology* is just one of the projects at Yerkes aimed at uncovering underlying mechanisms and pathogenesis of Alzheimer's disease. Walker is evaluating the immune response of squirrel monkeys to a vaccine targeting beta-amyloid protein. The goal is to see if the vaccine prompts the immune system to make antibodies against the protein without side effects. In another study, Rosen is looking at the structure of beta-amyloid protein in multiple primate species with the hope of identifying the correct target for new drugs and immunotherapy.

Rosen noted Yerkes has provided her with unparalleled access to resources for graduate-level research and training. Added Walker, "Yerkes is one of the only facilities in the world that offers researchers the resources to study chimpanzees across the entire lifespan, including behavior, biochemistry, physiology, molecular biology and disease pathology."

For more than seven decades, the Yerkes National Primate Research Center, Emory University, has been dedicated to conducting essential basic science and translational research to advance scientific understand-

ing and to improve the health and well-being of humans and nonhuman primates. Today, the center, as one of only eight National Institutes of Health-funded national primate research centers, provides leadership, training and resources to foster scientific creativity, collaboration and discoveries. Yerkes-based research is grounded in scientific integrity, expert knowledge, respect for colleagues, an open exchange of ideas and compassionate, quality animal care.

Within the fields of microbiology and immunology, neuroscience, psychobiology and sensory-motor systems, the center's research programs are seeking ways to: develop vaccines for infectious and noninfectious diseases, such as AIDS and Alzheimer's disease; treat cocaine addiction; interpret brain activity through imaging; increase understanding of progressive illnesses such as Parkinson's and Alzheimer's; unlock the secrets of memory; determine behavioral effects of hormone replacement therapy; address vision disorders; and advance knowledge about the evolutionary links between biology and behavior.



In addition to Rosen and Walker, study authors were Aaron Farberg, Marla Gearing, Jeromy Dooyema, Patrick Long, Daniel Anderson, Jean-Francois Pare, Timothy Duong, William Hopkins and Todd Preuss of Emory University, and Jeremy Davis-Turak, Giovanni Coppola and Daniel Geschwind of the David Geffen School of Medicine at UCLA.

EMORY ADRC FALL 2008 RESEARCH UPDATE:

The Personal Benefits of Research Participation...a reception to honor participants

Invitations have been mailed out - Be on the look out for yours!

CONTACT US

Emory Alzheimer's Disease Research Center

Wesley Wood Health Center
 1841 Clifton Road, NE
 Atlanta, GA 30329
 404-728-6950
<http://med.emory.edu/ADRC>

Memory Assessment Clinics

Wesley Woods Health Center
 1841 Clifton Road, NE
 Atlanta, GA 30329
 404-728-4936

Grady Memorial Hospital
 80 Butler Street, SE
 Atlanta, GA 30335
 404-616-4567

To Register for a Class:		
To Register for a Class call Susan Peterson-Hazan at 404-728-6273 at least one week prior to the beginning of each class.		
Event	Date	Location
Caregiver Challenges: Everything You Want to Know About the Middle Stage of Alzheimer's Disease <i>(Sponsored in part by a grant from the Wesley Woods Foundation)</i>	A 6-week class that meets: Friday: 10:30-12:00 October 31, November 7, 14, 21 and December 5 & 12	All Classes will be held at the: Wesley Woods Health Center 3 rd floor conference room 1841 Clifton Rd. Atlanta, GA 30329
Late Stage Alzheimer's Disease <i>(Sponsored in part by a grant from the Wesley Woods Foundation)</i>	A 4-week class that meets: Friday: 10:30 – 12:00 January 9, 16, 23, 30	
Early Memory Loss Group <i>(Co-sponsored by the Alzheimer's Association, Georgia Chapter)</i>	A 8-week class that meets: Friday 10:30 – 12:00 February 6, 13, 20, 27 and March 6, 13, 20, 27	



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National Institute on Aging ■ ◆ ★ ✨